

## **A Dying Person's Guide to Dying**

Roger C. Bone, M.D.

The central theme of the Home Care Guide for Advanced Cancer is that planning near the end of life is helpful. By thinking ahead about what could happen - and about how you will deal with problems if they do happen, you can create a better life and a better quality of life for yourself and for the people who love and care about you. What I have to say is for the person who, like myself, is dying. We, too, need to plan - to think ahead in order to fashion, out of the time remaining, the best of what is possible.

As I am dying from cancer, I have learned some things that I think are important for a dying person to know in order to plan. I am a physician, but what I have learned has little to do with my medical training. I have learned this as a person; perhaps my medical experience was helpful because I have paid close attention to the actions and reactions of people around me.

First, it is likely that you will be surrounded by persons who mean well but, in the end, you must die your own death. Dying can be considered a journey one takes alone with a crowd. Family and friends are the first to gather around you, and they offer the most comfort.

Here are some pieces of advice to remember in those first few days after you learn the bad news.

1. One or two people - probably family members - will make enormous personal sacrifices to help you. If you are married, your spouse is likely to do this, but don't be surprised if others - a daughter, a brother-in-law, or even a friend, step forward to offer extraordinary help. Be grateful, and accept help, from whatever source, graciously.
2. Some family members, but especially friends, will treat you differently. Even before you show signs of serious illness, people will have a different look in their eyes as they talk with you. You might consider this patronizing or over bearing. It may be difficult, but it is best to ignore their attitudes and treat them as you always have. They will come around to their normal selves when they get over the shock.
3. Happily accept all gifts from family and friends. It makes them feel better and you might receive something you really like and appreciate.
4. Don't be afraid to ask to be alone. We need time to be by ourselves. Some family and friends may feel driven to fill your every waking moment with activities; perhaps they are trying to 'take your mind off' your impending death, but they may also be doing the same thing for themselves.

5. Be your own counsel. No one, including your physician, religious counselor, spouse, or friends can understand 100% what you want and need. It surprised me that some people seemed to “bully” me with advice when they learned that I was terminally ill. We should remember Immanuel Kant’s advice to avoid accepting someone else’s authority in place of our own powers of reason. We are the ones who should be considering alternatives and making choices. We can, and should, ask for advice. Make telephone calls and read books - but ultimately, we should decide.
6. Slow down and ask your family and friends to slow down. There may not be a lot of time, but there is sufficient time in all but the most extreme cases to think, plan, prepare.

There are things you need to know from your doctors and other health care staff. You need not ask all of the following questions or ask them in this order. Still, these questions deal with crucial issues that need to be addressed and, hopefully, resolved.

1. What is my disease?

You should find out as much as possible about your disease. What it is it? How will it affect me? And very importantly, how will it cause my death? First, ask your physician. Additionally, many popular books are available in bookstores and libraries which can give you a basic sense of your disease process and disease terminology. National organizations, such as the American Cancer Society, and often local hospitals can provide brochures, video tapes, or even lay experts to help you and your family understand your particular disease. Ignorance is not bliss; the more you and your family know, the better able everyone will be able to cope with what is happening.

2. Should I seek a second opinion about my disease and my condition?

Seek a second opinion! A second opinion will relieve your mind and resolve doubts one way or another that a major mistake has not been made. More importantly, a second opinion will offer a slightly different perspective that may help everyone’s understanding. Don’t be embarrassed about asking for a second opinion or think that you will make your physician angry. Second opinions are perfectly acceptable, and many physicians are happy when their patients seek second opinions. The original diagnosis is usually confirmed, and you are then more prepared to follow prescribed treatments.

3. What health professional do I especially trust?

Search for and then trust in a single individual. This does not mean you should not listen to all health professionals and follow reasonable directions and advice. But focus on one individual as the final helper. This normally will be the specialist physician in charge of your case. However, you may know your family doctor better than you know your cancer specialist. If this is the case, your family doctor may be the one to choose. But, if you do, make certain that your family doctor knows that he or she is serving that role.

4. Why am I going into the hospital?

There are four basic reasons why a terminally ill person would be hospitalized, but not all four necessarily apply to every patient. They are: (1) to confirm the diagnosis and analyze how far the disease has progressed; (2) to provide treatment that can only be given in the hospital, (3) to treat a severe worsening of the disease; and (4) to treat the final phases of the disease, if this cannot be done at home or with hospice. You should know which applies to you so that you can understand why things are done to you and what benefits you can expect.

5. What are the hospital rules about terminally ill patients?

Hospitals and medical centers have written rules and procedures that outline in detail how the hospital will deal with terminally ill patients. These are not ‘treatment’ rules. These protocols or guidelines, as they are called, deal with how to handle end-of-life issues, such as whether the patient (or the patient’s family speaking for the patient) wishes extraordinary “heroic” measures to be used to keep the patient alive. Hospitals are obligated, and very willing, to share these protocols or guidelines with patients and families. Consider getting a durable power of attorney in which you name one or two people to make decisions or choices on your behalf if you should be incompetent or incapable of making decisions yourself. Read the ‘Do Not Resuscitate’ policies of the hospital. Death should be peaceful, and you should not ask for anything that gives you prolonged agony.

You should be aware that nurses and other hospital staff may not know that you are terminally ill. This fact may not be written in your chart, which can lead to conflicts between families and hospital staff. The family may assume that everyone in the hospital shares their grief, and will not understand the work-a-day attitude of nurses, dietitians, or others. It is okay for the family to tell the hospital staff that you are dying since they may not know.

6. What resources are available from the health care community?

Most hospitals have many services available to patients and families to help with nonmedical aspects of your care. These include social services and psychological, financial, and religious counseling. For example, a visit, before hospitalization, to the hospital financial counselor by a family member to check on insurance and payment plans is a wise move. In the rush to admit a patient, important information may not get recorded. A 15 minute meeting with counselors can avoid stress and anger over incorrect bills. Similarly, meeting with the hospital social worker may be very helpful in arranging home care. Use these services! The chapter on “Getting Help from Community Agencies and Volunteer Groups” has many useful ideas and strategies to help you get the help and resources you need.

7. What can I do if it seems that nothing is being done or if I don’t understand why certain things are done to me?

Hospitals, clinics, and doctors’ offices can be confusing places. You can begin to feel you have no control over what is being done to you, and you may wonder if anyone really

understands your case. This is the time to call the health professional who is your primary contact - the one you decided you fully trust - your physician specialist or family physician. Ask this person to explain what is going on. Have him or her paged or even called at home if your situation is very upsetting. It is the physician's responsibility to help you, and he or she will not be angry that you called. There are also some useful suggestions in the chapter titled "Getting Information From Medical Staff" to help you and your family deal with this problem.

8. How will I and my family pay for my treatment?

Financial professionals employed by hospitals understand billing and what may or may not be covered by Medicare, Medicaid, or private insurance. Consult them and be sure to ask every question to which you and your family need an answer. It is important that you and your family do not panic over billing. Ask for advice and help. There is additional information on this subject in the chapter on "Getting Help from Community Agencies and Volunteer Groups."

Sometimes the hardest part about dying is the effect it has on your family and friends. Helping them deal with your death helps you find peace and comfort. If you are not at peace with your death, ask the health professional you especially trust to help you find peace. That person will help or will get whatever help is needed. After all, it is the goal of all health professionals, to give you comfort and health during life and peace to you and your family at death.

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